International Consensus Statement on Public Involvement and Engagement with Data-Intensive Health Research

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International Consensus Statement on Public Involvement and Engagement with Data-Intensive Health Research

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Introduction

Data-intensive health research is a fast moving field in which public involvement and engagement (PI&E) is essential for developing socially acceptable and ethically robust processes and ensuring a social license for research practices. Nevertheless while some consensus is emerging around the importance of PI&E, commitments and practices are varied.

Objectives and Approach

Our objective was to identify a set of principles which would underpin international best practice in data-intensive health research.

A one-day consensus workshop was held in Manchester, U.K. in April 2017 and attended by 31 international participants from six countries, with a range of expertise relating to PI&E with data-intensive health research. Participants took part in facilitated discussions to identify key principles and a consensus statement was written to reflect the discussions at the workshop, this developed through iterative drafts on which all workshop participants as well as the four Farr Institute public panels were consulted.

Results

The consensus statement sets out key principles to establish a secure role for PI&E related to data-intensive health research internationally and to ensure best practice in its execution. While methods used may not vary greatly from PI&E with other types of research, or other policy areas, we have identified a number of particular features of data-intensive health research which make PI&E in this area worthy of special consideration. Often using data from multiple sources without explicit consent, PI&E in data-intensive health research is particularly important for raising awareness, for giving people a voice and for enabling people to participate in processes of research and governance. The consensus statement sets out the key principles to guide future best practice in PI&E with data-intensive health research.

Conclusion/Implications

The emergence of data intensive health research and the importance of the social contract upon which it relies, demands that we move beyond rhetorical commitments and engage anew with clearly stated principles to build PI&E into data-intensive health research at all levels.

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